

# Parents & Health Professionals in Partnership - Improving services in Haematology/Oncology Unit at the Women's & Children's Hospital.

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Women's & Children's Hospital

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- Importance of Involving Consumers
  - Health Service
  - Haematology/Oncology
- Examples of Consumer participation
- Benefits to health service
- Parent experience



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# Importance of Involving Consumers in Decision Making

## What does "Consumer" mean

- Individuals and collective interest
- Have legitimate rights, preferences and responsibilities
- Refers not only to direct user but also to potential user



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# Involvement of Consumers

- Supported by literature

Most effective way to get:

- Good information about needs
- Improve quality of health services



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## Recognition of Consumer Feedback

- Highly valued
- Incorporated in accreditation mechanisms
  - Australian Council of Health Care Standards



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## Consumer Participation

- Establishing a working partnership where clinicians and consumers become more aware of each others perspective about:
  - Changes in service delivery
  - Good working relationships in which issues can be resolved
  - Sharing problems and finding lateral solutions
  - Developing better communication and respect for each other



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# Consumer Participation

- Process of mutual adjustment
- Powerful tool for change

Requires:

- Commitment
- Appropriate skills
- Time to develop trust



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# Women's & Children's Hospital

- Integral to health service
- Key components of vision, philosophy, principles and goals
- Contributes to improved quality, informed decisions, social justice and sound management.



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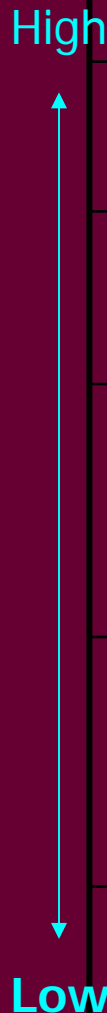
# Women's & Children's Hospital

## Consumer & Community Participation definition

*“Process of enabling consumers to be involved in health care decisions, depending on issues involved, their level of skill, support and resources available. Participation can be at the individual level through to health system level.”*

*Policy Quality management & Health Promotion – Consumer and Community Participation*

# Consumer Participation



Degree of Participation	Explanation
Consumer Control	Consumers make decisions
Partnerships	Decisions are made jointly by consumers and staff
Consultation	Consumer views are sought and incorporated into decision making
Information Seeking "Tokenism"	Staff seek information rather than opinions from consumers
Information Giving "Tokenism"	Information is provided to consumers



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# Ethical Guidelines Policy

- Ethically sound manner
- Confidentiality is maintained
- Choice to participate or not is respected
- Does not affect delivery of care in any way



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# Haematology/Oncology Unit

- Parent participation valued highly
- Essential component to any improvements

*Importance of knowing what parents want is crucial*





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## Parent Feedback

- Formal – participation on committees, projects, formal complaints
- Informal – suggestion boxes, verbal feedback and discussions

***Complaints: a catalyst for change that can make a difference for families***



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## Haemophilia Services

- Parent focus group 2000
  - Rural education
    - Outreach clinic providing education to health professionals in limestone coast area.
  - Transition to adult care
    - Transition package
    - Joint clinic with adult Haemophilia Treatment Centre



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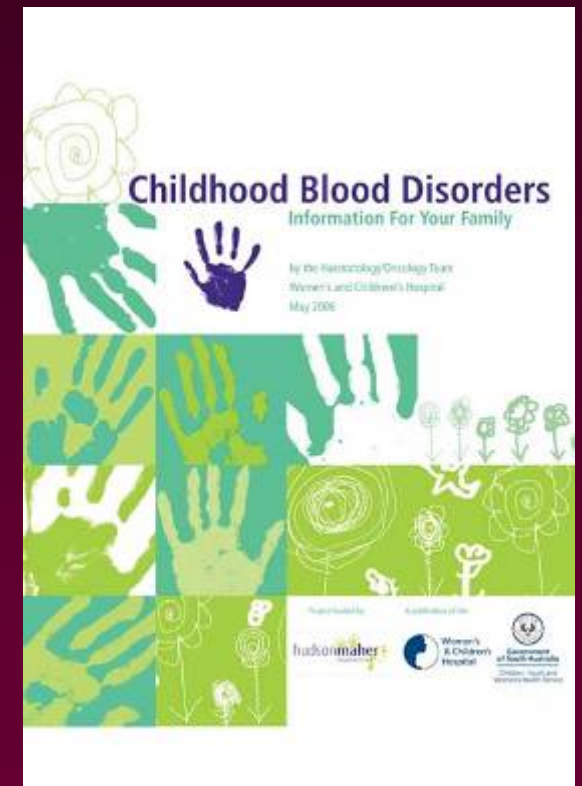
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## Involvement of Parents

- Identifying education and information needs
- Review of new health information for children with rare blood disorders
- Development of Information folder funded by Hudson Maher Foundation





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# Improving health Information for Young Adults

- Concept as a result of parent feedback
- Similar feedback from oncology, haemophilia and other areas dealing with young adults and chronic illness.
- Consumer consultation with young adults was essential to identify their needs



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## Overview of Project

- Funding through WCH Shops Auxiliary Health Promotion Incentive Grants
- Provide an opportunity for teenagers to discuss their experiences
- Develop resources to assist them to access appropriate health care information, negotiate the health care system, develop ongoing plan for service provision.



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## Process

- Consumers identified 12-18 years of age
- Invited to attend focus group
- Two groups held , split into Haematology or Oncology based on diagnosis
- Parent groups held simultaneously
- Payments to participants in acknowledgement of their contribution





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## Young Adult Feedback

- Health information they received
- What would assist them to be more independent
- What times did they feel they needed information about their health
- What supports would be useful



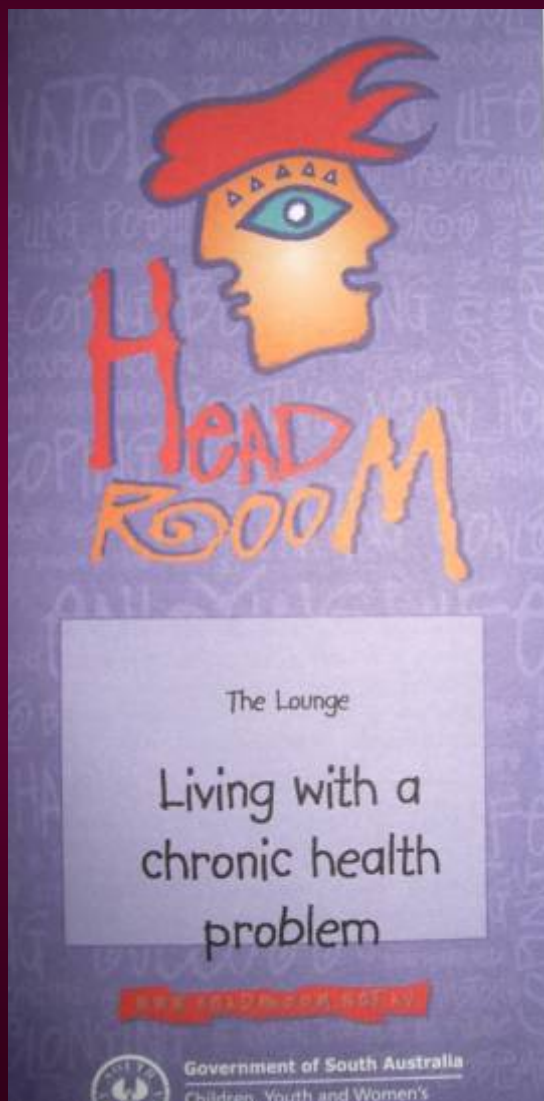
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# Outcomes





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# Outcomes Multi-disciplinary Education clinic – Haematologist session





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# Multi-disciplinary Education Clinic Physio session





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# Multi-Disciplinary Education Clinic Parent Group





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## Formation of Parent Advisory Group

- Provide greater role
- Parent advice and participation is the cornerstone for future improvements
- Invitation to all parents to participate
- Coordinated by Rachael Lumbert, Clinical Nurse.



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# Parent Advisory Committee

## Objectives:

- Participate in planning and development to maximise achievement of best practice outcomes
- To monitor and improve service to children undergoing radiotherapy
- Liaise with allied organisations and Government Depts.
- To advance awareness and understanding of special needs in both the public and private sectors of the community
- To provide a forum for parents



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## Parent Advisory Committee

- Vital role
- Concern group not representative of client group that is provided care.
- Active encouragement and support for haematology client group to participate is required to ensure their participation



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## Discovery Interviews

- New Initiative
- Nursing staff provided with opportunities to hear about families hospital experience
- Insight to nurses on the care they provide and changes they can make to benefit the families.



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## Benefits to Health Services

- Enables better functioning of teams
- Staff can feel better about their work and be more flexible
- Staff can learn what made a difference
- Staff get more practical information which enables better management of illness
- Creates a more open culture



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- Likely to be fewer complaints
- Shared philosophy
- Staff become more proactive in seeking and using consumer feedback
- Shared sense of problem solving
- Consumers become allies in service advocacy



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**Participating in partnerships is beneficial to both consumers and health service however there are also sacrifices for the individual.**

# Benefits to consumers

Motivation for involvement :-

- Managing own life with Haemophilia.
- Quest for knowledge

**‘Knowledge is Power’**

**Francis Bacon**

**‘Knowledge is Empowering’**

**Sharyn Wishart**

## HFA Council, 2001



**'Adversity brings knowledge.**

**And Knowledge wisdom'**

Welsh Proverb

## Benefits of becoming involved in your H.T.C.

- Contact with families
- Empowerment through Knowledge
- Increased confidence to manage life with Haemophilia.



## Ways to be involved:

- Forums
- Discussions with Doctors and HTC staff
- Groups; Young Families, Adolescents etc

# Future Directions

- Grouping Appointments
- Physio information sessions
- Working with schools
- Venous access workshop

My reasons for being involved.....



## Conclusion

*Communication between Health Care Providers and families is essential to ensure continual improvements in the quality of care provided to individuals and families.*



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## Acknowledgements

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